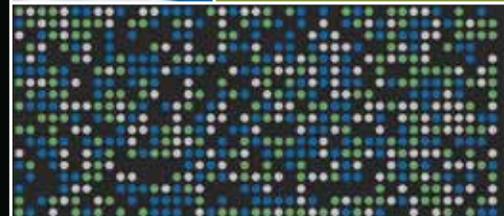


CENTER FOR  
GENETICS  
AND SOCIETY



2015 REPORT ON ACTIVITIES



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# CENTER FOR GENETICS AND SOCIETY

2015 REPORT ON ACTIVITIES

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## I . Introduction

In 2015, the Center for Genetics and Society was the leading public interest voice calling for the prohibition of heritable human genetic modification, playing a key role as controversy about this prospect emerged due to developments in gene editing techniques. We spoke at national and international symposia on this and other topics, expanded our news and social media presence, co-organized a film screening series, sponsored an online interview series, and pursued advocacy-oriented research projects via our Fellows Program. As in past years, we focused our efforts on building a new biopolitics grounded in social justice, human rights, and the public interest.

## II. Events and Presentations

During 2015, the Center for Genetics and Society co-organized events including the *Being Human in a Biotech Age* film series at the University of California, Berkeley, and the invitational Assisted Reproductive Technologies Working Group. We organized four sessions of *Talking Biopolitics*, our online series of conversations with cutting-edge thinkers. We gave invited presentations at 15 events ranging from a Rotary Club meeting, to an Institute of Medicine workshop on germline mitochondrial techniques, to the 500-person “International Summit on Human Gene Editing” organized by the National Academies of Sciences and Medicine in December.

### BEING HUMAN IN A BIOTECH AGE FILM SERIES

In fall 2015, we launched a new film series titled *Being Human in a Biotech Age* with two UC Berkeley-based groups: the Center for Science, Technology, Medicine, and Society; and the Department of Gender and Women's Studies / Chau Hoi Shuen Gender and Science Initiative. (Other UC Berkeley organizations sponsored individual events: the Doreen B. Townsend Center for the Humanities, the Department of Disability Studies, the Haas Institute for a Fair and Inclusive Society, and the Department of Sociology.) Our 2015 screening and discussion events were:

- September 29: *FIXED: The Science/Fiction of Human Enhancement*. Director Regan Brashear joined us for discussion afterward.
- October 13: *Made in India*. Directors Rebecca Haimowitz and Vaishali Sinha joined us to comment and answer questions after the screening via video conference.
- November 17: *Surviving Eugenics*. Directors Nicola Fairbrother and Rob Wilson joined us to comment and answer questions after the screening via video conference.

### TALKING BIOPOLITICS

*Talking Biopolitics*, our ongoing series of live web-based conversations with leading scholars, advocates, and artists about the social meaning of human biotechnologies, featured:

- February 27: Alexandra Minna Stern, CGS Advisory Board member and Professor of Obstetrics and Gynecology, American Culture, and History at the University of Michigan, interviewed Johns Hopkins University Professor of the History of Science Nathaniel Comfort about his book *The Science of Human Perfection: How Genes Became the Heart of American Medicine*.
- April 30: CGS Senior Fellow and UC Hastings Professor of Law Osagie Obasogie talked with UC Los Angeles Associate Professor in Public Policy Aaron Panofsky about his new book, *Misbehaving Science: Controversy and the Development of Behavior Genetics*.



## Events and Presentations

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- October 7: CGS Fellow and UC Davis Professor of Law Lisa Ikemoto spoke with Boston University Professor of Law George Annas about his new book (with Sherman Elias) *Genomic Messages: How the Evolving Science of Genetics Affects Our Health, Families, and Future*.
- November 19: Milton Reynolds of Facing History and Ourselves interviewed Rob Wilson, co-director of the just-released documentary *Surviving Eugenics*, which explores the history of eugenic sterilization in Western Canada and its ongoing impacts today.

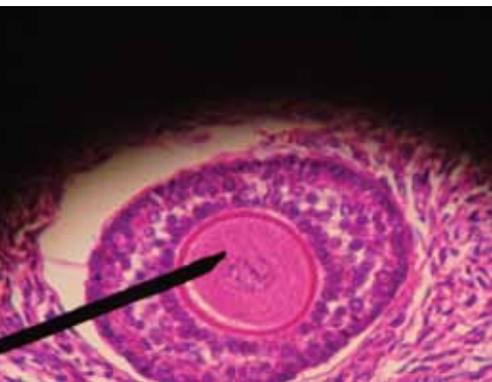
### ASSISTED REPRODUCTIVE TECHNOLOGIES WORKING GROUP

This collaborative effort with the Pro-Choice Alliance for Responsible Research, which grew out of CGS's 2010–2012 Tarrytown Meetings Initiative, allows us to play a leadership role among advocates for reproductive health, rights, and justice. It serves as a unique venue for sharing perspectives, news items, and advocacy and participation opportunities. In 2015, the ART Working Group grew to 80 invited members, including 15 from eight other countries. The listserv was increasingly, though still intermittently, active. We organized two well-attended online discussions:

- February 3: “Egg Freezing: The Fallout and the Future.” Our speakers were Miriam Zoll, author of *Cracked Open: Liberty, Fertility, and the Pursuit of High-Tech Babies*, and CGS's Jessica Cussins, with CGS consultant Emily Galpern moderating. Their presentations, and the discussion that followed, focused on the controversy that arose when Facebook and Google announced that they would cover egg freezing as an employee “benefit,” and the ways that family-unfriendly workplaces are coercing women to choose between career advancement and childbearing.
- July 30: “Global Surrogacy.” Amrita Pande, senior lecturer in the Department of Sociology at University of Cape Town and author of *Wombs in Labor: Transnational Commercial Surrogacy in India*, provided updates on surrogacy in India and its shift to Nepal when commissioning parents are gay. Isabel Fulda of GIRE (Grupo de Información en Reproducción Elegida) spoke about the surrogacy situation in Mexico and the strategies GIRE is pursuing in order to protect the rights of those involved. Michele Goodwin, Chancellor's Chair at UC Irvine School of Law and director of the Center for Biotechnology & Global Health Policy, discussed the coercive nature of international surrogacy and the financial incentives for international surrogacy companies.

### INTERNATIONAL SUMMIT ON HUMAN GENE EDITING

In December, we spoke by invitation at the 500-person International Summit on Human Gene Editing in Washington, DC, organized by the National Academy of Sciences, the National Academy of Medicine, the Chinese Academy of Sciences, and the UK's Royal Society. The summit was convened to discuss the scientific, ethical, and governance issues associated with research into human genetic engineering. Marcy Darnovsky presented comments on a panel titled “Societal Implications of Emerging Technologies,” was frequently quoted in subsequent news coverage of the summit, and was invited to comment in an op-ed for *The Guardian*.



## Events and Presentations

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### *Other Presentations and Workshops*

- In March, Marcy Darnovsky was invited to speak about human germline modification at the first public workshop of the Institute of Medicine’s Committee on Ethical and Social Policy Considerations of Novel Techniques for Prevention of Maternal Transmission of Mitochondrial DNA Diseases in Washington, DC. Her *Biopolitical Times* blog post about the session is titled “Incurious About Ethics?” Also in March, she presented on “The Biopolitical Imagination: A New Politics of Human Biotechnology” as part of the Science, Technology, Medicine & Society Speaker Series at the University of Michigan in Ann Arbor.
- In May, Marcy Darnovsky spoke on a panel titled “Human Germline Modification: Medicine, Science, Ethics, and Law” at Stanford University. Later that month, she was a “delegate” at “BEINGS 2015 – Biotech and the Ethical Imagination: A Global Summit,” a conference in Atlanta, Georgia, that billed itself as “a gathering of global thought leaders to reach consensus on the direction of biotechnology for the 21st century.” She wrote about the event in a *Biopolitical Times* blog post, “Tired Tropes and New Twists in the Debate about Human Germline Modification.”
- In June, Marcy Darnovsky and Osagie Obasogie spoke on the panel “Reshaping Public Discourse on Race and Health Disparities: Towards a Communications Strategy” at a meeting of the Working Group on Critical Race Theory and Scientific Methods in Santa Monica, California. Also that month, Marcy was a speaker for a summer seminar for high school teachers offered by Facing History and Ourselves, entitled “Race and Membership in American History: The Eugenics Movement.”
- In August, Marcy Darnovsky chaired a six-day seminar titled “Genetics and Inequality” at the European Forum Alpbach in Alpbach, Austria. Following the seminar, she gave a lecture titled “Should the Human Germline be Edited? Social, Policy and Ethical Considerations” at the Medical University of Innsbruck in Innsbruck, Austria.
- In October, Marcy Darnovsky spoke about genetically modified humans on a panel organized by the UC Berkeley Center for Science, Technology, Medicine and Society at the Bay Area Science Festival.
- In November, Marcy Darnovsky spoke at the international symposium “Genome on Demand? Exploring the Implications of Human Genome Editing” in Amsterdam, Netherlands, organized by the Netherlands Commission on Genetic Modification (COGEM). She also spoke about human germline editing on a panel titled “The Ethical Boundaries of Human Research” at a UC Irvine symposium called “The Challenge of Informed Consent in Times of Controversy.”
- In December, Marcy Darnovsky spoke at Xconomy’s annual Bay Area biotech forum on a panel titled “Finding the Ethical Line in 21st Century Biology.”



## III.

### Policy, Legislative, and Regulatory Initiatives

We anticipated that controversy about germline mitochondrial techniques would be a major issue in 2015, and that new gene editing tools would likely trigger renewed advocacy of all forms of human germline modification. But we did not anticipate just how explosive that issue would become. These two forms of human germline modification were the major focus of our policy work this year. We also worked on cross-border commercial surrogacy.

#### CRISPR AND HUMAN GERMLINE MODIFICATION

CGS played a key role in the high-profile controversy about human germline gene editing as the leading public interest voice calling for its prohibition. Immediately after the issue emerged in the spring, when scientists from Sun Yat-sen University reported that they had used CRISPR-Cas9 to modify non-viable human embryos, we held conference calls to brief our colleagues, and began fielding requests for comments from media.

In April, we wrote a letter to the White House Office of Science and Technology Policy (co-signed by Professor Troy Duster and by the Council for Responsible Genetics' Jeremy Gruber); in November, we organized an open letter calling for strengthened prohibitions on germline modification signed by more than 180 scholars, health practitioners, scientists, and public interest advocates. Also that month, we published the 50-page report written in collaboration with Friends of the Earth, which puts human gene editing into the context of broader developments in synthetic biology. In December, we spoke by invitation at the 500-person International Summit on Human Gene Editing in Washington, DC, on a panel titled "Societal Implications of Emerging Technologies."

Throughout the year, we addressed the issue via media citations (approximately 75 times); in CGS-authored writings for blogs, articles, op-eds, and letters to the editor; and in online materials that we circulated to the press and colleagues, including five press releases and a "Frequently Asked Questions" resource page on the CGS website.

Highlights include:

- In April, CGS issued its "Letter to Office of Science and Technology Policy" addressed to John P. Holdren, Director, Office of Science and Technology Policy and Co-Chair, President's Council of Advisors on Science and Technology and Eric Lander, Co-Chair, President's Council of Advisors on Science and Technology, from Marcy Darnovsky; Troy Duster, Chancellor's Professor of Sociology, University of California, Berkeley; and Jeremy Gruber, President and Executive Director, Council for Responsible Genetics.
- In late March, just after the controversy erupted about using CRISPR to "edit" human embryos, we organized two conference calls with colleagues to discuss developments and strategize responses. Close to 20 colleagues participated in each call.



## Policy, Legislative, and Regulatory Initiatives

*continued*



- In May, we added to the CGS website a continuously updated resource page on germline gene editing; a document entitled “Genetically Modified Humans? Seven Reasons to Say ‘No,’” outlining key arguments against human germline modification; and a Frequently Asked Questions document.
- In November, CGS organized a sign-on letter calling for strengthened prohibitions against using genetically engineered human embryos or gametes for reproduction. By December 31, the letter had been signed by 183 public interest advocates, scholars, and scientists.
- The majority of CGS’s media appearances during 2015 concerned human germline modification. We were cited approximately 30 times about germline mitochondrial techniques and about 75 times about germline gene editing.
- Staff, fellows, and long-time consultants published articles, op-eds, or letters to the editor on human germline gene editing in *The Guardian* (May, December), *The Hill* (March), *The Huffington Post* (May), *Kennedy School Review* (December), and *The New Yorker* (December).

### “THREE-PERSON IVF”

*(Also known as “nuclear genome transfer” or “germline mitochondrial manipulation”)*

CGS has been closely tracking this set of techniques since 2012. In anticipation of the UK Parliament vote that ultimately approved the techniques in February, we released an Open Letter to UK Members of Parliament as Vote on “Mitochondrial Donation” Approaches. In early March, Marcy Darnovsky gave an invited presentation about human germline modification at the first public workshop of the Institute of Medicine’s Committee on Ethical and Social Policy Considerations of Novel Techniques for Prevention of Maternal Transmission of Mitochondrial DNA Diseases in Washington, DC. We released three press statements on mitochondrial manipulation techniques, wrote six blog posts and an invited op-ed in the *Los Angeles Times* (“Britain is on the brink of a perilous vote for ‘three-person in vitro fertilization’”), and were cited about them some 30 times in a wide range of media outlets.

### CROSS-BORDER SURROGACY

Our work on surrogacy involved several publications: the report *Global Surrogacy Practices*; an excerpt of the report published at the Autonomous University of Barcelona; the co-authored article *What’s In a Name? Variations in terminology of third-party reproduction*; and a chapter for an anthology that is forthcoming from Zed Books. In addition, we worked with Our Bodies Ourselves on the online resource *Surrogacy360*, described in the following sections.

## IV. Advocacy-Oriented Research

CGS selects research projects that aim to fill key gaps in knowledge about the societal implications of human biotechnologies, and that support our strategic communications, policy, and networking activities. In 2015, CGS continued to work under a generous grant from the John D. and Catherine T. MacArthur Foundation on a set of collaborative projects focused on commercial egg retrieval and cross-border surrogacy, in partnership with the pioneering women's health organization Our Bodies Ourselves.

### *SURROGACY360*

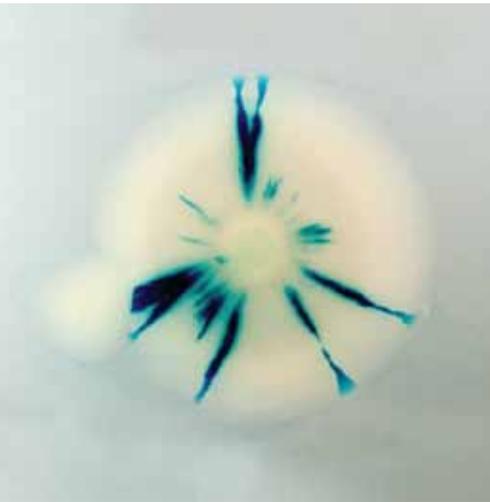
With Our Bodies Ourselves taking the lead, we undertook the development of the *Surrogacy360* website. The website provides independent information about cross-border commercial surrogacy as an alternative to the overwhelming amount of information sponsored by fertility clinics, intermediaries, and other industry sources that now dominate the online experience. *Surrogacy360* will feature news, research, and narratives related to surrogacy. It will serve as an independent, objective, and inclusive clearinghouse, gathering as much information as possible for people considering cross-border arrangements, experts working on the issue, and individuals simply interested in learning about the practice. We designed an early iteration of the website, and established an advisory team of advocates and researchers. CGS and OBOS see this effort in part as the basis of future work with LGBTQI organizations.

### *FORGOTTEN STORIES OF THE EUGENIC AGE*

*Forgotten Stories of the Eugenic Age* is a six-part *Biopolitical Times* blog series, researched and authored by CGS part-time staff member Natalie Oveyssi, that explores the lesser-known ways eugenics affected and engaged American lives during the first half of the twentieth century. Drawing from contemporaneous newspaper reports, the essays focus on better babies and fitter families contests; eugenics in romance and marriage counseling, as well as divorce proceedings; and high-profile cases of doctors who refused medical care to newborns with disabilities and performed outright eugenic infanticide.

### *GLOBAL BIOPOLICIES COMPENDIUM*

We completed updating three sections of CGS's online compendium of country-level policies, currently called the BioPolicy Wiki, on surrogacy, egg retrieval for assisted reproduction, and egg retrieval for research. We plan to re-launch BioPolicy Wiki in a non-wiki format as part of our CGS website overhaul in 2016.



## V. Media and Communications

CGS's media and online profile continued to expand in 2015. Our communications efforts aim to increase public, policymaker, and media understanding of biopolitical issues; build CGS's reputation as a thought leader and go-to source for information and commentary; and provide information resources for colleagues, journalists, and students. Our work includes original writing from books to op-eds to blog posts, frequent appearances by our staff in a wide range of media outlets, and a robust social media and online presence.

### PUBLICATIONS

#### Books and reports

- *Global Surrogacy Practices*, by Marcy Darnovsky and Diane Beeson, was published in January by the International Institute of Social Studies of Erasmus University. A lengthy excerpt appeared in November in the publication of the organization *AFIN* (Adopciones, Familias, Infancias) at the Autonomous University of Barcelona.
- *Extreme Human Genetic Engineering: Reclaiming Biotechnologies for the Common Good*, published in November, was a collaborative project with Friends of the Earth. Long-time CGS consultant Pete Shanks was the lead author. We will use this report in the coming year to bring our concerns about species-altering technologies to other environmental organizations.
- "What's in a Name? Terminology on Cross-Border Surrogacy," by CGS Fellow Diane Beeson, Marcy Darnovsky, and Abby Lippman, was published in *Reproductive Biomedicine Online* in December.
- Marcy Darnovsky and Osagie Obasogie's edited anthology, *Beyond Bioethics: Toward a New Biopolitics*, is forthcoming from University of California Press.
- CGS-associated authors wrote three chapters that will be published in a forthcoming anthology from Zed Books titled *Wombs for Rent: Transnational Surrogacy, Human Rights and the Politics of Reproduction*.
  - "Mapping Feminist Views on Surrogacy," by former CGS staff member Emma Maniere
  - "Gestational Surrogacy: How Safe?," by CGS Fellow Dian Beeson and Abby Lippman
  - "Governing Transnational Surrogacy Practices: What Role Can National and International Regulation Play?," by CGS consultant Sonia Allan, based in part on her research for CGS's Biopolicy Wiki



## Publications

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### Op-eds and articles

CGS-associated writers published commentaries and articles in media outlets including *The New York Times*, *The Guardian*, *Los Angeles Times*, *The Hill*, and *The Huffington Post*.

- Pete Shanks, “Bad-Boy Scientism,” *The Huffington Post* (January 14)
- Jessica Cussins, “Direct-to-consumer genetic tests should come with a health warning,” *Pharmaceutical Journal* (January 15)
- Marcy Darnovsky and Jessica Cussins, “Britain is on the brink of a perilous vote for ‘three-person in vitro fertilization’,” *Los Angeles Times* (February 8)
- Marcy Darnovsky, “23andMe’s Dangerous Business Model,” *The New York Times* (March 2)
- Jessica Cussins, “The Blurred Lines of Genetic Data: Practicality, Pleasure and Policing,” *The Huffington Post* (May 8)
- Charis Thompson, Ruha Benjamin, Jessica Cussins, and Marcy Darnovsky, “Innovation and equity in an age of gene editing,” *The Guardian* (May 19)
- Diane Beeson, Marcy Darnovsky, and Abby Lippman, “What’s in a name? Variations in terminology of third-party reproduction,” *Reproductive Biomedicine Online* (September 15)
- Marcy Darnovsky, “Genetically engineered children?,” *The Hill* (December 1)
- Marcy Darnovsky, “Human gene editing is a social and political matter, not just a scientific one,” *The Guardian* (December 4)
- Jessica Cussins, “Should we genetically modify our children?,” *Kennedy School Review* (December 7)
- Marcy Darnovsky, “Genetic Control” [letter to the editor], *The New Yorker* (December 14)



## Publications

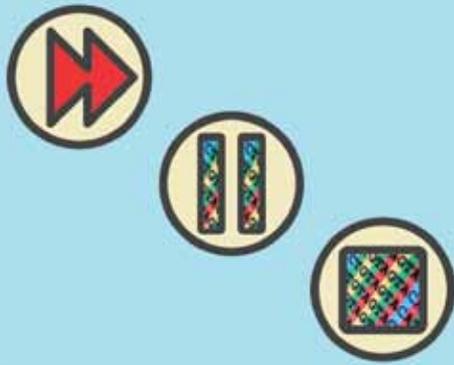
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### **Biopolitical Times blog**

The CGS blog *Biopolitical Times* averaged about 4500 visits per month in 2015. Staff, fellows, interns, and colleagues wrote some 80 blogs for *Biopolitical Times* in 2015. Of these, 20 were authored by 13 guest contributors: George Annas, Naomi Cahn, Katayoun Chamany, Nathaniel Comfort, Colleen Cordes, Gwen D’Arcangelis, Sayantani DasGupta, George Estreich, Jaydee Hanson, Lisa Ikemoto, Ricki Lewis, Gina Maranto, and Stuart Newman.

The following is a selection of blog posts by CGS staff and consultants:

- UK May Be Poised for “Historic Mistake” on “3-Person IVF,” Jessica Cussins (January 22)
- Key Questions About the Social and Ethical Implications of Nuclear Genome Transfer or “3-Person IVF” Techniques, Jessica Cussins (January 22)
- Mitochondrial Mission Creep and the Cloning Connection, Pete Shanks (February 14)
- With World Watching, UK Allows Experiments to Genetically Alter Babies, Jessica Cussins (March 4)
- A Tipping Point on Human Germline Modification?, Jessica Cussins (March 19)
- Calling for “More than a Moratorium” on Human Germline Modification, Jessica Cussins (April 9)
- Incurious about Ethics?, Marcy Darnovsky (April 9)
- Synthetic Biology and Human Germline Engineering, Pete Shanks (April 9)
- Stopping or Selling Human Germline Modification?, Pete Shanks (May 7)
- Tired Tropes and New Twists in the Debate about Human Germline Modification, Marcy Darnovsky (May 28)
- UK Seeks Regulatory Advice for “Mitochondrial Replacement,” Fails to Mention Cross-Generational Implications, Jessica Cussins (June 17)
- The Science and Ethics of Genetically Engineered Human DNA, Pete Shanks (June 18)
- Talking About the Germline, Pete Shanks (July 8)
- Slipping Into Eugenics? Nathaniel Comfort on the History Behind CRISPR, Elliot Hosman (July 23)
- What Will 120 Million CRISPR Dollars Buy?, Elliot Hosman (August 13)
- CRISPR–Cpf1: Hype by Association, Elliot Hosman (October 2)
- The CRISPR Germline Debate: Closed to the Public?, Elliot Hosman (October 15)



## CGS in the News

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- Gene Editing and Eugenics (Opinions Vary), Pete Shanks (October 29)
- CRISPR Gene Editing: Proofreaders and Undo Buttons, but Ever “Safe” Enough?, Elliot Hosman (November 19)
- Livetweeting #GeneEditSummit: Democratized Debate or Segregated Conversations?, Elliot Hosman (December 10)
- Weak Arguments For Modifying the Human Germline, Pete Shanks (December 10)

### CGS IN THE NEWS

CGS staff members were quoted about 150 times by print, radio, television, and online media on a diverse range of topics. In addition to the dozens of media citations on topics related to germline mitochondrial techniques and germline gene editing, high-profile publications cited us on a range of other topics including genetic testing, DNA forensics, cross-border surrogacy, race and genetics, cloning, and egg freezing in a wide variety of outlets, including:

- high-circulation newspapers and news agencies (*The New York Times*, *Washington Post*, *Wall Street Journal*, *San Francisco Chronicle*, *Newsday*, Associated Press, Reuters, CNN)
- print and online magazines (*The Economist*, *USA Today*, *The New Yorker*, *National Geographic*, *VICE*, *Buzzfeed*)
- science and popular science outlets (*Scientific American*, *New Scientist*, *Science AAAS*, *Science Magazine*, *Science News*, *Nature News*, *MIT Technology Review*, *Genetic Engineering News*, *ScienceAlert*)
- radio and television shows (*KKSF*, *NPR*, *NPR’s On Point*, *KPCC*, *Al Jazeera America*, *KQED Radio*, *CBC Radio*, *Religion & Ethics Newsweekly* (*KQED & PBS*))

In 2015, we issued nine press statements on topics including human germline gene editing, germline mitochondrial techniques, and cross-border surrogacy.

The following is a selection of notable CGS media citations, organized by topic:

#### Human inheritable genetic modification

- Marcy Darnovsky was cited in “Critics Lash Out At Chinese Scientists Who Edited DNA In Human Embryos,” Rob Stein, *NPR* (April 23)
- Marcy Darnovsky was cited in “Chinese Gene-Editing Experiment Creeps Out Scientists,” Maggie Fox, *NBC News* (April 23)
- Marcy Darnovsky was cited in “Ethics of embryo editing paper divides scientists,” Sara Reardon, *Nature News* (April 24)



## CGS in the News

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- The Center for Genetics and Society was cited in “Chinese paper on embryo engineering splits scientific community,” Jocelyn Kaiser and Dennis Normile, *Science Magazine* (April 24)
- Marcy Darnovsky was cited in “US ‘will not fund research for modifying embryo DNA,’” James Gallagher, *BBC* (April 30)
- Marcy Darnovsky was cited in “Ethics of Gene Editing,” Betty Rollin, *Religion & Ethics Newsweekly, KQED & PBS* (July 2)
- Marcy Darnovsky was cited in “Der Gottes-Code,” Ulrike Baureithel, *Der Freitag* [Germany] (July 7)
- Marcy Darnovsky was cited in “The ethical and social concerns of modifying our DNA,” Devin Powell, *Washington Post* (August 3)
- The Center for Genetics and Society was cited in “Genome editing: The age of the red pen,” *The Economist* (August 22)
- Marcy Darnovsky was cited in “British scientists seek to edit the genes of embryos; bioethicists warn of potential dangers,” Ariana Eunjung Cha, *Washington Post* (September 18)
- The Center for Genetics and Society was cited in “Everything you need to know about why CRISPR is such a hot technology,” Dominic Basulto, *Washington Post* (November 4)
- Marcy Darnovsky was cited in “The Gene Hackers,” Michael Specter, *The New Yorker* (November 16)
- Marcy Darnovsky was cited in “China’s Bold Push into Genetically Customized Animals,” Christina Larson, *Scientific American* (November 17)
- Marcy Darnovsky was cited in “Future of human gene editing to be decided at landmark summit,” Ian Sample, *The Guardian* (November 28)
- Marcy Darnovsky was cited in “Editing the Human Genome,” Owen Bennett Jones, *BBC Newshour* (November 28)
- The Center for Genetics and Society was cited in “Humans will be ‘irrevocably altered’ by genetic editing, warn scientists ahead of summit,” Sarah Knapton, *The Telegraph* (November 30)

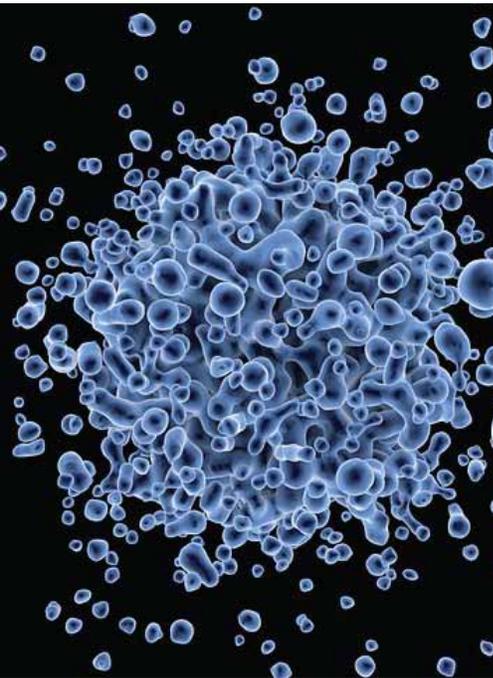
## CGS in the News

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- Marcy Darnovsky and Pete Shanks were cited in “US scientists urge ban on human genetic modification,” Ryan Rifai, *Al Jazeera America* (November 30)
- Marcy Darnovsky was cited in “Le génie génétique face au risque eugéniste,” Corine Lesnes, *Le Monde* (November 30)
- Marcy Darnovsky was cited in “Dare we edit the human race? Star geneticists wrestle with their power,” Sharon Begley, *STAT* (December 2)
- The Center for Genetics and Society was cited in “Are You Ready for Genetically Modified Babies?,” Hilary Bruek, *Fortune* (December 2)
- Marcy Darnovsky was cited in “Is the era of designer humans getting closer?,” Fergus Walsh, *BBC* (December 3)
- Marcy Darnovsky was cited in “5 Reasons Gene Editing Is Both Terrific and Terrifying,” Karen Weintraub, *National Geographic* (December 3)
- Marcy Darnovsky was cited in “Gene editing: Don't use in human reproduction, prestigious panel says,” Lisa Krieger, *San Jose Mercury News* (December 3)
- Pete Shanks was cited in “Debate begins over ethics of genetic editing,” Michael Cook, *BioEdge* (December 5)
- Pete Shanks was cited in “Broad Institute Licenses CRISPR/Cas9 Gene Editing Technology To Biotech Firm Transposagen,” Katherine Derla, *Tech Times* (December 13)

### Mitochondrial DNA replacement (“three-person IVF”)

- Marcy Darnovsky was cited in “Britain moves toward allowing creation of babies from DNA of 3 people,” Christina Boyle, *Los Angeles Times* (February 3)
- Marcy Darnovsky was cited in “UK lawmakers approve ‘3-parent babies’ law,” Laura Smith-Spark, *CNN* (February 3)
- Marcy Darnovsky was cited in “U.K. Parliament approves controversial three-parent mitochondrial gene therapy,” Gretchen Vogel and Erik Stokstad, *Science* (February 3)
- Marcy Darnovsky was cited in “UK becomes first country to approve three-parent in vitro fertilization,” *Airtalk*, *KPCC* (February 3)



## CGS in the News

*continued*

- Marcy Darnovsky was cited in “UK Set to Legalize Babies With DNA From 3 Parents,” Irene Noguchi, *KQED Radio* (February 6)
- Marcy Darnovsky was cited in “When Will ‘3-Parent Babies’ Come to the U.S.?,” Dina Fine Maron, *Scientific American* (February 6)
- Marcy Darnovsky was cited in “Mitochondrial gene therapy passes final U.K. vote,” Gretchen Vogel, *Science* (February 24)
- Marcy Darnovsky was cited in “UK OKs Three-Parent IVF,” Bob Grant, *The Scientist* (February 25)
- Marcy Darnovsky was cited in “Three-Parent IVF: What’s The Hurry?,” John Farrell, *Forbes* (February 28)

### Assisted reproductive technologies

- Marcy Darnovsky was cited in “IVF booster offered in Canada but not US,” Alison Motluk, *Canadian Medical Association Journal* (January 14)
- Marcy Darnovsky was cited in “States aren't eager to regulate fertility industry,” Michael Ollove, *USA Today* (March 18)
- Marcy Darnovsky was cited in “4 Questions About The Fertility Industry’s Lack Of Oversight,” Joy Pullmann, *The Federalist* (March 19)
- Marcy Darnovsky was cited in “A Modern Woman’s Burden,” Natalie Lampert, *New Republic* (March 20)
- Marcy Darnovsky was cited in “Lightly regulated in vitro fertilization yields thousands of babies annually,” Michael Ollove, *Washington Post* (April 13)
- Marcy Darnovsky was cited in “U.S. couple stuck in Mexico due to surrogacy snafu,” Rafael Romo, *CNN* (May 8)
- Marcy Darnovsky was cited in “Is It Worth Your Time and Money to Freeze Your Eggs?,” Tracy Egan Morrissey, *Vice Media Channel Broadly* (August 24)
- Marcy Darnovsky was cited in “The Messy, Complicated Nature of Assisted Reproductive Technology,” J. Wesley Judd, *Pacific Standard* (September 28)
- CGS Fellow Lisa Ikemoto was cited in “California Judge Orders Frozen Embryos Destroyed,” Andy Newman, *The New York Times* (November 19)
- The Center for Genetics and Society was cited in “Screening sperm donors for autism? As an autistic person, I know that’s the road to eugenics,” Ari Ne’eman, *The Guardian* (December 30)



## CGS in the News

continued

### Personal genomics and genetic testing

- Marcy Darnovsky was cited in “Ranchers Test for Better Genes to Get Better Beef, Better Prices,” Jacob Bunge and Kelsey Gee, *Wall Street Journal* (January 6)
- Marcy Darnovsky was cited in “Anne Wojcicki’s quest to put people in charge of their own health,” Stephanie Lee, *San Francisco Chronicle* (February 28)
- Marcy Darnovsky was cited in “These Are All the Things That Could Go Wrong with 23andMe’s Drug Development,” Kari Paul, *Motherboard* (March 19)
- Marcy Darnovsky was cited in “Warn people of genetic health risks, says deCODE boss,” Andy Coghlan, *New Scientist* (March 25)
- Marcy Darnovsky was cited in “DNA ‘Printing’ A Big Boon To Research, But Some Raise Concern,” Rob Stein, *NPR* (May 7)
- Marcy Darnovsky was cited in “What’s Your DNA Worth? The Scramble To Cash In On the Genome,” Alex Lash, *Xconomy* (October 20)
- Elliot Hosman was cited in “As Companies Collect More Health Data, Cops Will Ask To See It,” Stephanie M. Lee, *Buzzfeed* (November 5)

### Other

- Marcy Darnovsky was cited in “Controversial DNA startup wants to let customers create creatures,” Stephanie M. Lee, *San Francisco Chronicle* (January 3)
- Marcy Darnovsky was cited in “Should a genetics company plan to create new creatures?,” Tim Sandle, *Digital Journal* (January 12)
- Pete Shanks and Marcy Darnovsky were cited in “Les vertiges du transhumanisme,” Corine Lesnes, *Le Monde* (February 12)
- Marcy Darnovsky was cited in “California Stem Cell Agency Symposium: ‘Vague Fears’ vs. Potential Genetic Alteration of Human Race,” David Jensen, *California Stem Cell Report* (June 11)
- Osagie Obasogie was cited in “Blinded by Sight: Can blind people be racist?,” Fu’ad Lawal, *Pulse.ng* (June 20)
- Osagie Obasogie was cited in “DNA forensics not as infallible as investigators claim — But not because of science,” Andrew Porterfield, *Genetic Literacy Project* (June 29)
- Osagie Obasogie was cited in “Blind people can be racist, too, study says,” Carina Storrs, *CNN* (August 30)
- Osagie Obasogie was cited in “Seeing Others: Is Racial Prejudice Innate or Learned?,” Chelsea Leu, *California Magazine* (September 22)



#### CGS ONLINE

**Website and blogs:** In 2015, traffic to the CGS website increased by more than 45% from the previous year, and now averages close to 31,000 visits per month. Our blog, *Biopolitical Times*, received about 4,500 visits per month. CGS staff writers added several posts per month to Genetic Crossroads, the CGS blog on *Psychology Today's* website.

**Newsletter and News Scan:** In 2015, CGS's twice-monthly newsletter *Biopolitical Views & News* had more than 4,600 subscribers. CGS also produces a twice-weekly digest of important news items that facilitates our press, media, and other work, and is shared with close colleagues worldwide.

**Social Media:** As of January 1, 2016, CGS had some 5,600 followers on Twitter (@C\_G\_S), up approximately 20% since January 1 of the previous year. CGS's YouTube Channel has received more than 60,000 views since it went online five years ago. The CGS Facebook page has more than 2,100 followers, up 30% since January 1, 2015.

## VI. Budget and Funding

CGS's adjusted expenses for 2015 were \$530,937. Current funding for CGS comes from the Appleton Foundation; the Marisla Foundation; the John D. and Catherine T. MacArthur Foundation; the Lyman B. Brainerd, Jr. Family Foundation; the Heimbinder Family Foundation; the Winiarski Family Foundation; and individual donors. Complete financial reports are available on request.



## VII.

### Who We Are

The work of the Center for Genetics and Society is carried out by regular staff, part-time associates, Fellows, an Advisory Board, regular consultants, and contributors to our *Biopolitical Times* blog.

#### STAFF

As of December 31, CGS had three full-time regular staff:

- Marcy Darnovsky, PhD, Executive Director
- Charles Garzón, MA, Director of Finance and Administration
- Elliot Hosman, JD, Senior Program Associate

#### THE CGS FELLOWS PROGRAM

Senior CGS Fellow Osagie Obasogie and the three colleagues whom we invited last year to take part in our expanded Fellows Program undertook a number of research projects to provide important information for a range of the biopolitical work that CGS and others are doing. Their work is summarized here.

- Osagie Obasogie, JD, PhD, is Professor of Law at UC Hastings College of Law with a joint appointment at UC San Francisco Department of Social and Behavioral Sciences. With Marcy Darnovsky, he is co-editing the anthology that will be published by UC Press. He is also working on a project about police DNA databases.
- Gina Maranto, MA, is Director of the Ecosystem Science and Policy undergraduate program and coordinator of the graduate program in Environmental Science and Policy at the University of Miami's Leonard and Jayne Abess Center. Working with her students at the University of Miami, she completed an online survey and is working on a publication about American women's knowledge of and participation in egg harvesting, and their perception of its risks.
- Lisa Ikemoto, JD, LLM, is Martin Luther King Jr. Professor of Law at UC Davis. She is working on three projects related to egg procurement and commercial surrogacy. The first demonstrates that fertility, stem cell, and cloning research are now generating significant demand for women's eggs. The second documents that few researchers have disclosed information about how the eggs they use are acquired, including health outcomes for the women. The third involves mapping the global markets for eggs and surrogacy.
- Diane Beeson, PhD, is Professor Emerita of Sociology, California State University, East Bay. She took the lead on an article (co-authored with Abby Lippman and Marcy Darnovsky) that explores the controversies around terminology in discussions of cross-border surrogacy. She has also written a chapter about under-studied health risks of surrogacy for women and infants that will be published in a forthcoming anthology by Zed Books.



## Who We Are

*continued*

### ADVISORY BOARD

CGS is honored to have a distinguished Advisory Board to help guide our work. Current members are:

- Francine Coeytaux, MPH (Advisory Board chair), reproductive and public health expert; founder, Pacific Institute for Women's Health.
- Dorothy Roberts, JD, George A. Weiss University Professor of Law and Sociology and Raymond Pace and Sadie Tanner Mossell Alexander Professor of Civil Rights, University of Pennsylvania Law School and Department of Sociology.
- Alexandra Minna Stern, Professor of American Culture at the University of Michigan, and holds appointments in the Departments of History, Women's Studies, and Obstetrics and Gynecology.

### PART-TIME STAFF ASSOCIATES

CGS's work in 2015 was ably supported by several summer and part-time staff associates:

- Jonathan Chernoguz is an undergraduate at University of California Berkeley, majoring in political economy and minoring in public policy.
- Natalie Oveyssi graduated summa cum laude in spring 2015 with a BA in Sociology from University of California Berkeley, where she served as editor-in-chief of the undergraduate humanities and social science research journal.

### CONSULTANTS AND CONTRIBUTORS

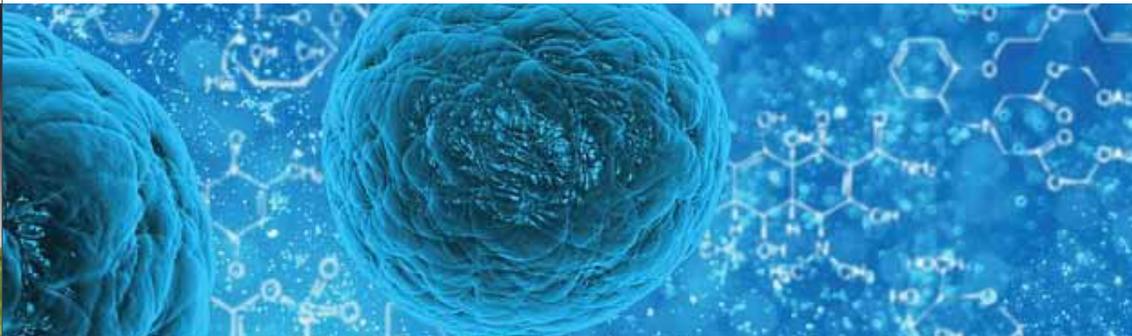
A number of consultants play key roles in CGS's work.

- Pete Shanks, MA, long time consultant has worked with the Center for Genetics and Society since its earliest days. He is the author of *Human Genetic Engineering: A Guide for Activists, Skeptics, and the Very Perplexed* (Nation Books) and a regular contributor to Biopolitical Times.
- Jessica Cussins was Project Associate at the Center for Genetics and Society from 2012-2015. She is currently pursuing a master's degree in Public Policy from the Harvard Kennedy School of Government.
- Emily Galpern, consultant at Emily Galpern Consulting, was Project Director on Reproductive Health, Rights and Justice at Center for Genetics and Society and at Generations Ahead from 2005-2009.

### ORGANIZATIONAL STATUS

The Center for Genetics and Society is a project of the Tides Center, a 501(c)3 organization funded by individual contributions and philanthropic foundations.





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